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ABSTRACT

This paper uses personal profiles to highlight major events across the past five decades that have affected the lives of individuals with mental retardation and their families. Each of the scenarios provided represents a creation of prototypical families, communities, school climates, issues, and social attitudes during a particular decade. Barbara is a young adult woman who was involved during the 1960s in the initial phases of integrating individuals with mental retardation into the workforce. Jose, a second-language learner, went through special education testing processes and the public educational system during the 1970s. Terrell is a young man brought up by his teenage mother in a single parent household during the 1980s. Rachel, born with fetal alcohol syndrome, is involved in a School-to-Work Youth Apprenticeship in the 1990s. Finally, Mitchell, born with Down syndrome, faces the future. The profiles are intended to help society reflect on what has helped and hindered employment and independent living for people with mental retardation. For each decade, an appendix outlines the legislative policy relevant to students and adults with disabilities, philosophy, research breakthroughs, and practices in schools and the community. (Contains 52 references.) (CR)

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Forty Years of Progress: Where Have We Been? Where Are We Now?

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Forty Years of Progress: Where Have We Been? Where Are We Now?

If we look to the not so distant past, we see a history of lost opportunities in employment and the ability to meaningfully contribute to society for individuals with mental retardation (Murphy & Rogan, 1995). Many issues surround why these individuals have not been more infused within our societies, particularly the employment sector.

As advocates for facilitating change, we must continually revisit what we have done, what we are currently doing, and where we want to go in order to make productive changes. As we enter a new millennium it may be helpful to depict some past and more recent profiles, snapshots if you will, of the lives, trials and accomplishments of individuals with mental retardation. Therefore, the purpose of this article is to examine perspectives that have set us upon this current stage. Specifically, we will highlight major events across the past five decades. We will use personal profiles to pinpoint policies, philosophy, and practices that impacted the lives of individuals with mental retardation and their families. We hope this examination will shed light on past and present attitudes, and even misperceptions of individuals with mental retardation as competitive employees and members of society.

Each of the following scenarios represents a creation of a prototypical family, community, school climate, issues and social attitudes during that particular decade. Barbara is a young adult woman who during the 1960s was involved in the initial phases of integrating individuals with mental retardation into our workforce. Jose, a second-language learner, went through special education testing processes and the public educational system during the 1970s. Terrell is a young man brought up by his teenage mother in a single parent household during the 1980s. Rachel, born with fetal alcohol syndrome, is involved in a School-to-Work Youth Apprenticeship in the 1990s. Finally, what does the future hold for Mitchell, born with Down syndrome in the 1990s?

These profiles are intended to make us reflect upon snapshots of what has helped and hindered employment and independent living for people with mental retardation. By comparing a core of specific information relative to each decade, we can better assess where we've been, our current status, and where we may go in the future.

The 1960s

In 1966, Barbara Jerry, a 23-year old woman with mild mental retardation, lived at home with her family and worked at a nonprofit sheltered workshop five days per week. Individuals with mental retardation were seen as incapable of community employment, and needed to be separated from *normal* workers and settings. Sheltered workshops in the U.S. offered special care in a protective environment to help *retardates* like Barbara obtain the skills and discipline to achieve some productivity. Barbara's nonprofit workshop paid her *piece-rate* for gluing cardboard cylinders, a subcontract obtained from a local business whose *normal* workers frowned on such repetitive tasks. Barbara's parents were largely responsible for her having the opportunity for a small degree of independence. For individuals with less actively involved parents, the outcomes were not as positive.

The Jerrys, a typical working class family, had three children. Barbara, the second child, was born in 1943 without incident. Even though she looked *normal*, she crawled and walked much later than her same age peers. At age three, her parents became concerned as they were still awaiting her first words. After some testing, the family physician determined that Barbara was *mentally subnormal* or *mentally deficient*, terms, which had recently replaced *feeble-minded*. Doctors said that Barbara would be incapable of adapting to a normal environment and would not be able to maintain an existence independent of supervision. The doctors stated that this condition was most likely due to some kind of biologic pathology. Her parents were urged to find a place to leave her (i.e., an institution) so they could lead their own lives. Many authorities encouraged institutionalization to treat the inevitable adaptive behavior deficits of these children.

The Jerrys went against their doctors' wishes and kept Barbara at home. In 1950, when Barbara was seven, Mrs. Jerry read *The Child Who Never Grew* by Pearl S. Buck. She found strength in Mrs. Buck's disclosure of feeling bewildered and ashamed about her own daughter with mental retardation. She also enjoyed reading Dale Evans Rogers' book, *Angel Unaware*, about her daughter with Down syndrome, the proceeds from which helped launch the National Association for Retarded Children (NARC). In 1954, the NARC organized radio and television spots sending a new message about mental retardation. The NARC's first executive director

persuaded President Eisenhower to declare a National Retarded Children's week.

As Barbara grew to school age, her parents were unwavering in their refusal to place her in an institution. By the mid- to late 1950s, many parents who had chosen to keep their children with retardation at home combined forces and began demanding alternative services and placements. Thus, Barbara's primary school years were spent attending an educational program in a facility sponsored by the local NARC chapter. The Jerry family participated in fund-raising activities to keep this special school afloat. As these parents worked together toward a common goal, they became more solidified and started advocating more for their children's rights.

In 1960, at age 17, Barbara finally entered a public high school, which had just created special *Work Study* classes for students with mental retardation. This Work Study program focused on the development of *work attitudes* and *general work behaviors*. Vocational tasks were broken down into their component parts, and Barbara practiced each part repeatedly until she gained proficiency. By the end of the school year, Barbara learned to independently gather her materials and to wash, rinse, and dry the sink, counter, and floor in her classroom. After replacing her materials, she would ask the teacher to *check* each of the separate steps involved in these tasks. They used a task analysis checklist to evaluate her performance. Barbara also studied *prevocational* skills like personal hygiene, communication skills, and how to follow instructions. In 1963, officials met at Barbara's school and arranged for her to *advance* to a sheltered workshop. Barbara wanted to be a cosmetologist. However, the workshop was the only postsecondary opportunity available to her.

See 1950's – 1960's Timeline

The 1970s

In 1976, Jose, a stocky 16-year old stood 5 feet 4 inches tall. Jose attended a class each day in his neighborhood high school. The students in this class were given the label Educable Mentally Retarded (EMR). One year earlier, landmark legislation, Public Law 94-142, was passed granting children with disabilities the right to a free appropriate public education (FAPE) in the least restrictive environment (LRE). As a result, each day in the United States approximately 728,000 individuals with mental retardation received special education services in

public schools, and no longer in separate educational facilities.

Jose was born in 1960, the first son in the Garcia family after four daughters. In 1955, Mr. and Mrs. Garcia moved to Los Angeles from Mexico. The Garcias could read and write English well enough to perform their respective jobs. They wanted their children to learn English, but they were most comfortable conversing in Spanish. The Garcias were part of a growing number of U.S. Citizens with "Limited English Proficiency."

Jose had a healthy, happy childhood. It wasn't until he entered school that he began to have difficulties. School was confusing to him. Few books in Jose's home had pictures depicting princesses, elves, or talking animals who wore people's clothes. Other children in his class seemed familiar with these storybook characters, but these concepts were foreign to Jose. Language and communication was difficult; Jose was corrected often. Actually, Jose's mistakes were common characteristics (e.g., code switching) of children for whom English is a second language (ESL). However, none of Jose's teachers had background or training in how to recognize such characteristics.

When frustrated, Jose would stamp his feet, and soon the Garcias were notified that Jose had *behavior problems* that were causing him to fall behind academically. It was suggested that he be *retained* and repeat first grade. At the beginning of what should have been his second grade year, he was given an IQ test in English -- not his native language. The Garcias were shocked and bewildered to find out that Jose was mentally retarded. He didn't look like a *mongoloid,* and his physical development seemed appropriate. In any event, the Garcias now faced the task of learning about mental retardation and educational options for their child. Jose's teacher told the Garcias to contact the Morenos, a couple quite active in the local NARC (National Association of Retarded Citizens) chapter.

The Garcias were relieved and soon learned from the Morenos about many promising options for raising a child with mental retardation. Mrs. Moreno shared the re-printed dairies of two young men with Down Syndrome brought up in devoted, stimulating families. The Garcias felt assured Jose could flourish in their caring home environment. After all, Jose was walking, talking, and could dress and feed himself without assistance. He did not have violent outbursts or aggressive behaviors.

Next the Garcias faced the task of finding a school that would take Jose. The Morenos knew of a few special schools in the greater Los Angeles area, but none were located in the Garcias' neighborhood. So, Jose traveled miles each day to school until 1972 (Jose was 12) when his neighborhood school started an EMR class.

At this time, much was happening in the larger disability community. Geraldo Rivera exposed the atrocious conditions at Willowbrook State School (1972) which validated the Garcias' decision to keep Jose at home. Institutions and *special segregated* schools were under attack for being dehumanizing. The Garcias heard of new litigation; in particular, two cases involving their State of residence, California. Two to three times more children of Spanish-surname and African-American families were in EMR classes than were represented in the total population. These law suits addressed the cultural and linguistic biases of IQ testing often leading to segregation of Mexican-American and African-American children.

Until 1973, IQ had been used as the sole criterion in the diagnosis of MR, yet current trends questioned this. *Adaptive behavior* was ultimately added to the MR diagnostic criteria, coinciding with the passage of Public Law 94-142 which also required that multiple tests be administered and reviewed by a multidisciplinary team. The American Association on Mental Deficiency (AAMD) changed the IQ criterion from one to two standard deviations below the mean and levels were now termed mild, moderate, severe and profound. Jose entered high school in 1975 when this new definition was incorporated into Public Law 94-142 declassifying 85% of the individuals who formally met the criteria for students with mental retardation. Jose's IQ of 69 allowed him to continue attendance in his EMR class. Approximately half of his classmates were sent to general education settings, which was met with much trepidation by students and teachers.

Mr. Garcia heard that about a new program, Special Olympics. He had worried that Jose had no activities or friends outside of school. This seemed like the perfect opportunity. Jose signed up, they had practice each weekend and competition a few times per year. Jose now seemed well on his way. His parents had learned about the special education system. He was receiving some functional academics and vocational instruction in his school, and he was involved in Special Olympics on the weekends.

See 1970's Timeline

The 1980s

In 1987, Terrell Jackson, a tall thin 18 year-old, was a sophomore in a community-based vocational program. Now that law *mandated* "transition services," schools across the country were responsible for assisting students with disabilities in moving from the safety and security of school to the opportunities and risks of adult living.

A fifteen year-old, Yolanda Jackson, gave birth to Terrell in 1969. She was young and single, and did not admit she was pregnant or see a doctor until she was 6 months along. Terrell was born 2 months premature at 3 pounds 5 ounces and needed to remain in the hospital a few weeks. Terrell was frequently cross and ill the first few years of his life.

When Terrell was two years old, Yolanda applied for Aid to Families with Dependent Children (AFDC) and within a year moved into her own apartment in a public housing community. Yolanda's apartment was small and somewhat damp. The faucets constantly dripped. It was loud and rarely a night would go by without them being awakened. Yolanda didn't know if Terrell's lack of vitality was due to a medical problem or their living situation.

With help from AFDC, she could finally take Terrell to a doctor who would accept Medicaid. The doctor explained that there might be some developmental delays, which is common for low birth-weight babies. The doctor asked many questions, even something about paint chips. The doctor explained that lead poisoning had been associated with learning problems. While it was impossible to tell conclusively, the doctor was concerned that combinations of factors were working against him. Therefore, she recommended a program, Head Start.

Terrell was enrolled in a Head Start program at the Community Center. Terrell's Mom was encouraged to stay and participate. Together Yolanda and Terrell would make books using pictures from magazines. They had no books at home, so Yolanda enjoyed learning how to make games and other things so inexpensively. It made Yolanda feel good to *contribute* to Terrell's class.

When Terrell started Kindergarten in the fall of 1975, he didn't speak much and typically just pointed. Terrell often didn't understand things or was afraid to ask. The more his teacher pushed, the more he withdrew. Terrell learned to become almost invisible.

By second grade, he was referred for testing and determined eligible to receive special education services. The teacher stated that his speech was delayed and that he was not yet reading, and that he often slipped into a fantasy world. She used words like *hyper-vigilant* and *withdrawn* to describe his behaviors. It was no surprise to Yolanda that the tests indicated that Terrell was slow. He'd always been a little behind other children his age, but mental retardation? Terrell didn't have facial features or traits like other children with mental retardation. She remembered the doctor talking about developmental delays, but she never thought of these delays as *retardation*.

A meeting was called to develop Terrell's Individual Education Program (IEP). Yolanda had a difficult time making it to this meeting. She worked at a Day Care Center and these meetings cost her a day's pay during a stressful time. Not only did Yolanda have to come to terms with Terrell's retardation, but their Medicaid and AFDC cash payments ended. She told herself over and over again, they would be all right as long as neither of them became ill.

It was decided that Terrell should enter a special education classroom to "reduce extraneous environmental stimuli" that might be frightening him. His IEP goals included self-care goals such as feeding, dressing, and personal hygiene. Yolanda thought he may need a speech therapist, but didn't know to ask for such *related services*. After all, these people were experts in special education, they must know what's best. Who was she to question their decisions?

During the 1980s, calls for educational reform were commonplace. Schools were criticized for being dangerous, ineffective, and for having too many students exit functionally illiterate. The focus in special education shifted to a more functional curriculum in which reading, language, and math occurred in the context of daily "real life" activities. It was believed that for students to perform functional skills in the community, learning must occur in the community.

Terrell and his peers, the first group of students to go entirely through their schooling

under Public Law 94-142, were part of the National Longitudinal Transition Study of Special Education Students mandated by Congress. Terrell's life seemed to be quite typical of the study's findings. Two years after he graduated high school with a certificate of completion, he was employed part-time, earned just slightly above the minimum wage, and still lived at home. Like a large proportion of his cohort, Terrell was African-American and poor. Unlike one-third of his classmates, he did not drop out of school. Terrell attended occasional dances and social activities sponsored by Easter Seals and The Arc. Almost every Saturday Terrell would go with one or both of his best friends from school to the park, the mall, or his favorite – the movies. He even happened upon movies depicting individuals with challenges similar to his own.

See 1980's Timeline

The 1990's

In 1996, Rachel Gordon stood at 5'3" with beautiful long brown hair and green eyes. She was well known by classmates in general and special education for her sense of humor and willingness to try new things. She was also involved in a School-to-Work Youth Apprenticeship 20 hours a week at a hospital.

Rachel was one of approximately 594,025 individuals with mental retardation who received special education services in their neighborhood public schools. She also received help completing her general education assignments in science and social studies. Because many assignments involved cooperative learning groups, Rachel was able to succeed with the help of her peers. In her general education mathematics class she was assigned a peer tutor, Melanie. Melanie received an elective credit for helping students like Rachel. Melanie was senior class vice president and enjoyed Rachel's company. A few times, they had done things together outside of school. Melanie introduced Rachel to her friends. Rachel's circle of friends expanded, and she even felt comfortable calling a few to go out after school or on weekends. One new friend was a co-worker at the hospital. Everyone seemed to like Rachel.

Rachel's beginnings were not so rosy. She was born with Fetal Alcohol syndrome (FAS). Her birthmother, Sarah began drinking during her teens. By the time Sarah was 20 she had graduated to cocaine and marijuana. At age 25, she became pregnant with Rachel. Sarah knew

that alcohol abuse is the leading cause of mental retardation. Unfortunately, Sarah, like 739,000 other women who used drugs during pregnancy that year, didn't worry because she was a *recreational user.* Like many women addicts, Sarah lived with a man in an abusive and exploitive relationship. She feared telling him she was pregnant afraid that he'd leave her. Also, like many addicted mothers, Sarah did not seek prenatal care for fear she'd be reported to authorities for illegal drug use. As a result, she did not see a doctor until she could no longer hide it. Throughout the pregnancy she was stressed, anxious, and suffered from depression.

When Rachel was born, she had mild facial abnormalities, a smaller-than-normal head, and she was a preemie -- tiny. Sarah's blood alcohol level was checked. Doctors became concerned when they also found traces of cocaine in her urine. Sarah, with great hesitation and guilt, admitted to doing cocaine that may have precipitated the premature labor. Rachel was one of the 2.6 million alcohol exposed and some 460,000 drug exposed infants born that year. With increased drug use, was also an increase in out-of-home placements for infants and toddlers.

Social Services was called almost immediately and Sarah was required to talk to a nurse and social worker. Her boyfriend was infuriated that *undue* attention was brought to their lives. As Sarah agonized over what to do, he was becoming more abusive. She could handle the abuse; after all she was an adult. But, what about the baby? Sarah, more depressed, agreed to put the baby up for adoption.

At about thirteen months of age, Rachel's situation turned for the better. A family had been identified and thrilled about the possibility of adopting a child. Fourteen months later, Rachel was placed in the Gordon's home, and formal adoption procedures began. This was one of the 127,000 adoptions in the U.S. that year, 15% of which were adoptions of children in foster care.

In elementary school, Rachel had many therapeutic and social/behavioral needs. These needs were addressed in a self-contained classroom. Mental health workers provided services in the classroom and at home in order to include school personnel and the family in her social skills development and behavioral self control, her most pressing needs. Even though Rachel had many friends and good social skills, she was strong-willed and got stressed-out quite easily. Teachers often described her behavior as noncompliant.

During high school, Rachel and her parents experienced great many things. Her parents listened eagerly as parents from The Association for Persons with Severe Handicaps (TASH) spoke about social inclusion -- something of which they would later become strong proponents. With high school also came an interest and motivation to get a job and make money. Rachel's older sister taught her to ride the city bus explaining to Rachel how *uncool* it was to have your parents drive you places. Her sister felt it was important for Rachel to get around on her own. The Gordons agreed. They wanted her to be more independent as she moved into high school.

At the beginning of her senior year, goals were created to prepare Rachel for a Tech Prep Nurse's Assistant Program at a community college. Her long-term goal was to be responsible for routine personal assistance in a long-term care facility or in a hospital. After a few years of supported training, she would take the exam to become a certified Nurse Assistant, usually completed in 6 months yet, the Gordons asked the student support department for an extended period of study. The director of the community college's Programs and Services for Students with Disabilities agreed to this arrangement. Opportunities abounded.

Rachel became involved in the *Best Buddies* program sponsored by Special Olympics. She had been a Special Olympian for 6 years, but also wanted to participate in the social aspects of the programs; not just the athletic aspects. Rachel enjoyed meeting people outside her high school. She found out that there was a *Best Buddies Colleges* program that promoted friendships between college students with and without mental retardation. Rachel thought it may be a good idea to get advice from someone not paid to be her counselor.

Rachel was a great model of someone who had not only overcome many odds in her life but also had an independent spirit and was willing to go the distance. She had determination and a family who had faith in her. She had a hard but successful growth from childhood to young adulthood; and she was now entering into a new world. Rachel was becoming what all parents would love to see their own children become self-sufficient, hard working, and happy.

See 1990's Timeline

The Millennium: The Year 2000

The Trumans agreed their careers came before starting a family, but with both in their 40s

they wondered if they'd waited too long. In 1992, however, they did finally get their wish when Mitchell was born. The doctors explained that his small flat nose, small mouth, and slanted eyes with epicanthic folds are the physical characteristics of Down Syndrome. Mitchell was one of the 125,000 children born with mental retardation in the U.S. that year. Doctors further explained that the extent of Mitchell's cognitive impairment, or mental retardation, would not be known for several years. The Trumans felt blessed that Mitchell did not also suffer from a heart defect or intestinal malfunction common abnormalities for children with Down's.

In 1992, the AAMR came out with a new definition distinguishing levels of MR according to the intensity of support needed. Whether or not this would have an impact upon Mitchell and his parents are yet to be seen. In the year 2000, few states were using the definition to determine special education eligibility; and even fewer were discussing mental retardation in terms of levels of supports needed.

Before Mrs. Truman left the hospital a parent advocate contacted her about a weekly support group. They learned that Down Syndrome is evident in 1 out of every 600 births and that rate increases as the parents get older. The Trumans were so grateful to not be alone or so terribly misunderstood. Their guilt and disappointment was fading away as other parents talked about their children with such joy at these meetings. During the first 2 years of Mitchell's young life, the Trumans were made aware of the significant changes in service provision for the 0-3 population. Maternity leave benefits had also changed. With better early intervention, better nutrition, and hopes for children born to older parents, Mitchell's life looked promising.

The previous decade, the 1990s, had been inundated with technological advances. So, it is not surprising that the Trumans found a growth chart published by *Pediatrics* on the Internet. Parents needed normative comparisons for their children with Down Syndrome like parents of children without disabilities who use growth charts to determine their child's progress. The Trumans had also accessed web sites regarding MR and parent support groups. Eventually Mr. Truman, a computer software engineer, created a web site for parents of children with Down Syndrome. By the year 2000, quite a list had been placed on the web site.

What is Mitchell's vocational potential? What opportunities await him? It is clear that as the decades have progressed, so too have the issues and concerns regarding individuals with

mental retardation as employees do.

Despite the undeniable progress of the past 40 years, many problems remain. The majority of adults with mental retardation continue to be excluded from the nation's work force, unable to obtain or maintain employment. Yet, at this time in our history, we have a chance to dramatically improve the employment opportunities of Americans with mental retardation. Various political, economic, and social forces are currently combining to create a unique opportunity that we should not disregard. We must expand upon those principles we know to be successful and summon the courage and resources necessary to solve the problems we have too long ignored.

These chronicles briefly described those policies, philosophies, and practices that have significantly impacted the education, the services afforded, and the overall lifestyles of individuals with mental or cognitive impairments. What is needed now more than ever is a philosophy that drives independence, that helps define our curricula, that effect teaching strategies, that prepare the students in our public schools to enter society, that help to make strong, healthy individuals who fit within our communities (the system).

The quality of life, attitudes, and individual perspectives of the lives of individuals with mental retardation have changed significantly since the early years of special education. We have moved from terms like feeble-minded, idiot, imbecile, and moron, to cognitive disability. We have gone from views of deviancy and deficiency to views of natural differences and at times, even a celebration of diversity. We have seen progress from institutionalization to community living, We are moving from fear to acceptance. A vast array of potential and opportunities currently afforded most people with disabilities has opened a world of new life options. Choices regarding college, independent living, transportation, and even marriage have altered the world of people with disabilities. In a current PCMR report, one individual is quoted as saying:

> "For the first time in my life I am experiencing the quality of life that is standard for a person without disabilities. I have been given the opportunity to live my life as I choose. I have a good life, not just by the standards of any person. I now realize what I have been deprived of and what I can expect in the future. The limits that were placed on

me have been eliminated, although I still have my disability."
(Hewitt, & O'Nell, 1998a, p.1.)

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1950's - 1960's Timeline

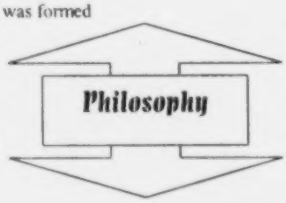
Legislation

⇨1963: Vocational Education Act of 1963

⇨1964: Civil Rights Act

⇨1965: Elementary and Secondary Education Act, with special programs to assist disadvantaged & "handicapped"

⇨1966: Bureau of Education for the Handicapped was formed



Conceptualization

⇨1958: **Weschler, intelligence based**

- Borderline IQ = 70-79
- Moron IQ = 50-69
- Imbecile IQ = 30-49
- Idiot = 29 & below

⇨1959: **Dr. Rick Heber, Chair - Amer. Assoc. on Mental Retardation, Terminology & Classification Comm.** ground breaking def. w/ intell. Ability & adapt. beh

- Borderline IQ = 69-83
- Mild MR IQ = 52-67
- Moderate IQ = 36-51
- Severe MR IQ = 20-35
- Profound MR IQ = 19 ⇩

⇨1964: **Scheerenberger, educability expectations**

- Dull Norm IQ = 75 – 80/90 Educable IQ = 50-75
- Trainable IQ = 20-49
- Custodial IQ = 20 ⇩

Research

⇨**Emergent Research**

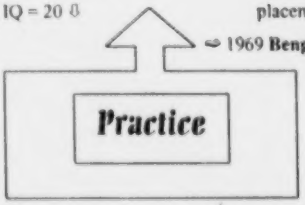
- post-school adjustment
- post-institutional adjustment
- vocational rehabilitation outcome

⇨1966: **President's Committee on Mental Retardation**

⇨ 1968: **Lloyd Dunn**

- efficacy of students with mild disabilities placing in special classes
- questioned the use of "*disability labels*"
- recommended labels describing the *nature of education* services
- emphasized importance of special education placement for students with more severe disabilities

⇨ 1969 **Bengt Nirje** publishes on normalization



Programs

⇨**Work Study Programs**: focus on work attitudes & work study skills including;

- prevocational in sheltered workshops
- job tryout or vocational adjustment
- supervised vocational placement
- adjusted academic plan coordinated w/ vocational program

⇨**Self-contained special schools and classes**: proliferate in schools yet advocates such as Dunn (1968) questioned if educational and civil rights were being violated as such

⇨**Sensory Training**

⇨**Personality Development**

⇨1968: **Special Olympics** founded by Eunice Kennedy Shriver

⇨1954: **The ARC** founded by group of concerned parents

⇨1961: **President Kennedy calls for a national agenda on MR**

Incidence

⇨1948-1966: **up 400%** MR's served in public schools

⇨1960's: **90%** all schools provided MR programs; all but 10% segregated

⇨1960's: **145,230** with mild MR received rehabilitation services (VR)

⇨1967: **over 1/3** of all special educators in nation teach students with MR

⇨1969: **26,762** were gainfully employed, increase of **651%**

⇨1969: **96,604** secondary students with MR in workstudy **60-80%** of these are from low status backgrounds

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1970's Timeline

Policy

Legislative

1971: **Compulsory sterilization** – 21 states

1973: **Vocational Rehabilitation Act** - Civil Rights

1973: **Section 504 of the Rehabilitation Act** - prohibits federally funded programs from discriminating against individuals with disabilities

1973: **$879 million federal funds** committed for individuals with disabilities

1975: **PL 94-142** - FAPE in LRE

1977: **marriage** for adults with MR prohibited in 41 states; can be **legally voided**

Litigation

1970: **Diana v Board of Education** - must be tested in native language

1972: **Larry P. v Riles** – culturally biased IQ testing

1972: **Pennsylvania Association for Retarded Citizens v Pennsylvania (PARC v Penn.)** – deinstitutionalization ,"inhumane conditions" and right to treatment

1972: **Mills v Board of Education** – due process and funding

Philosophy

Conceptualization

1970's: **Center for Independent Living and People First** - rise in advocacy

1970's: start **neighborhood schools**; still segregated

1970's: persons can be diagnosed as having MR at one point in their lives and not at some other time, changes in intellectual functioning, adaptive behavior, or changes in expectations of society may result in de-classification reducing upper IQ limit from 85 to 70, the largest group previously considered mentally retarded were no longer considered such & the definition now required **two standard deviations** below the mean

1970's: **Jane Mercer** publishes *Labeling the Mentally Retarded* - questions labeling and identification of diverse students as mentally retarded

1970: **Evelyn Deno**, introduces **Cascade of Services Model**

1972: **James Gallagher** , introduces *"individualized education contracts"*

Research

1970: **"The Six-Hour Retarded Child"** - President's Commission on Mental Retardation

1970's: **"Try another way"** – Mark Gold, applied behavior analysis, behavior modification

1970's: **Deno** - questioned the efficacy of categorical criteria

1970's: **misclassification** and **exclusion**

1970's: **teen pregnancy** highest ever

1972: **Geraldo Rivera** - exposed **Willowbrook State School**

1973: **AAMD definition** was incorporated into **PL 94-142**;

1973: **Fetal alcohol syndrome (FAS)** - recognized, and alcohol determined to cause disabilities

1978: becomes illegal to sell lead paint in United States

~~Philosophy~~ Practice

Programs

1976: **CEC** approved **Division of Career Development** Brolin's **Life Centered Career Education**

Incidence

1970's: **3%** identified with MR despite definitional changes; **3%** IQs below 70

1974: **Office of Career Education** established
1975: **Work study contracts,** with *PL 94-142*, declined due to shift in responsibility to special education rather than vocational rehabilitation

1970's: **2 to 3 times more Spanish** surnamed and **African American** in **EMR** classes compared to total population
1975: > **half** children with disabilities not receiving appropriate educational services; **one million** excluded entirely from the school system
1975: **85% MRs declassified with PL 94-142's** new definition of individuals eligible for sped services for
1976: ~ **$31.00 per week** - workshop clients at *subcontract* earning this supplemented by public assistance (**SSI - $147.00**)
1977: **32,851** students with MR served in work study programs (declined in 80's to 25,121)
1979: **U.S. Department of Labor** describes typical client in workshop as a white, 25 year old mentally retarded male never married living in a dependent type living arrangement or group home
1979: **U.S. Department of Labor** estimates that the **100,000** adults served in rehabilitation day programs earned on average **$160.00 per year**

1980's Timeline

Policy

Legislation

- 1983: **OSERS** issues a national priority for **transition issues**
- 1984: **Public Law 98-527, the Developmental Disabilities Act** 1984 Congress, defines **developmental disability**

Litigation

- 1983: ***City of Cleburne, Texas v Cleburne Living Centers*** - **prejudices & stereotypes** cannot justify discrimination
- 1984: ***Daniel R.R. v State Board of Education*** - **LRE**
- 1988: ***Honig v Doe*** – **expulsion/suspension**
- 1988: ***Timothy W. v Rochester School District*** - **educability**

Philosophy

Conceptualization

- 1980's: **Adaptive behavior** defined
- 1980's: **Manual on Terminology and Classification in Mental Retardation, 1977 Revision of American Association On Mental Deficiency (AAMD)** – definitions and classifications aligned to AAMD
- 1980's: **Adaptive Behavior Scale (AAMD ABS),** rating scale of adaptive behavior to measure an individual's routine personal, community, and social responsibility as well as interpersonal behaviors
- 1984: **developmental disability** defined - severe, chronic disability
- 1989: **Christopher Burke**, a young man with Down syndrome, begins acting in a TV series, "Life Goes On."

Research

- 1980: **Bellamy, Sheehan, Horner and Boles** report - adults in rehabilitation day programs lack vocational training and placement
- 1980's: **Adaptive behavior** - further examination and research leading to development of **Balthazar Scales of Adaptive Behavior** and the **Vineland Social Maturity Scale**

Practice

Programs

- 1980's **Community-based special education**
- 1980's: **Supported employment**
- 1980's: **Job Coach**
- 1989: **Best Buddies**

Incidence

- 1980: **25,121** students with MR served in work study; down from *32,851* in 1977
- 1980: **100,000** adults with severe disabilities (SD) are served in rehabilitation day programs
- 1988: **78% of all African Americans** (AA) with disabilities do *NOT* participate in labor force, full or part-time; **38% less** earning potential for AA with SD than all other AA; **77% of all Hispanic Americans (HA)** with disabilities do *NOT* participate in the work force; HA with disabilities

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earn **29% LESS** than HA without disabilities

- 1985 -1987: **Postschool results up to 3 years out of secondary school:**

  · **25%** MR enrolled in post-secondary since high school;

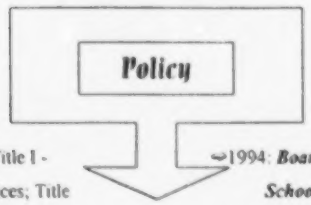
  · **5.7%** enrolled in post-secondary vocational since high school;

  · **40.8%** competitively employed;

  · **14.8%** living independently;

  · **$8,145.00** is the average annual total compensation (from *The National Longitudinal Transition Study of Special Education Students, Statistical Almanac, Vol. 1: Overview*, 1990)

1990's Timeline



Legislation

⇨1990's: **Americans with Disabilities Act,** Title I - Employment; Title II - Public Services; Title III - Public Accommodations; Title IV - Tele communications; Title V - Miscellaneous

⇨1990: **Education for All Handicapped (EHA) Act** amended by Congress and renamed it the Individuals with Disabilities Education Act (IDEA)

Litigation

⇨1994: ***Board of Education, Sacramento City Unified School District v Holland*** - LRE determination

⇨1998: Harry ***County School District v P.F.*** - FAPE education under current IDEA and residential placement due to consistent 24-hour behavior management plan

Conceptualization

⇨1990's: **Association of Higher Education and Disability (AHEAD),** organization involved in the development of policy and in the provision of quality support services to serve the needs in higher education

⇨1990: **People First Language** is recognized and used in federal laws

⇨1990: **"Zero to three,"** - provided services to infants and toddlers, and their families

⇨1990's: **Self-determination and full citizenship** - common value goals to guide teaching students with MR

⇨1990'S: **Present Levels of Performance (PLOPs)** - current student performance levels in IEPs from a *"strengths based"* model

⇨1997: **Job Fairs** - job seekers with disabilities meet and interview and interview with area employers

⇨1997: **Awards** and **Recognition** for individuals who have made exceptional contributions to public awareness of empowerment and employment of people with disabilities

- **President's Award** (*Just Break One*)
- **Evan Kemp Entrepreneurship Award** (*Narrative Television Network*)
- **Justin Dart Achievement Award** (*U.S. Department of Education, Office of Special Education and Rehabilitation Services)*

⇨1997: **Promoting Small Business and Self-Employment Opportunities,** the first year of the program, the President's Committee awarded a contract to the ***World Institute on Disability*** to plan and conduct a working **forum** in 1998 that will produce a **national agenda** on entrepreneurship and disability

Research

⇨1999: **31% of accommodations costs negligible** for People with Disabilities; **19% cost $50.00** or less and; **70% cost** under **$500.00**

⇨1994; **Job Accommodation Network** estimates company savings:
38% saved $1 - $5,000;
34% saved $5,000 - $20,000; and
23% saved $20,000 - $200,000;
40 times more spent to support individuals with disabilities NOT working than to prepare them to find employment

⇨1995: **National Council on Disability** – study on FAPE and IDEA found that:

- low expectations concerning students with disabilities impeded implementation of IDEA; and
- an insufficient focus on applying research -based proven methods of teaching and learning

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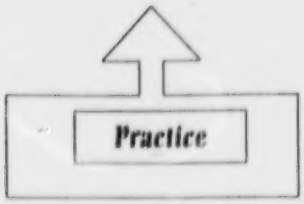

Programs

⇨1990's: **OSERS** report on education:

- 56% youth with disabilities graduate from high school
- 39% drop out each year
- 7% leave before completing high school ("age-out")
- 50% of our nation's annual class of students with disabilities find employment... of those only 50% are employed full-time

Workforce Recruitment Program, Job Accommodation Network (JAN), pre-screened college students with disabilities to fill summer or permanent hiring needs;

- **Rehabilitation Services Administration (RSA),** funds state vocational rehabilitation agencies, oversees programs that help people with physical or mental disabilities obtain employment via RSA's major formula grant program
- **I-NABIR, The Association of Projects with Industry,** federally funded programs that provide employment preparation and job placement services under the guidance of employers;

⇨1990's: **Promoting Employment Opportunities for Persons with Cognitive Disabilities,** employment partnerships that focus upon "white collar" industries for people with mental retardation ;

⇨1990's: **Individualized Family Service Plan (IFSP)** plan for students from birth through two

Incidence

⇨1990's: **40,000** students with developmental disabilities transition out of school

⇨1992: the census found:

- 49 million American had disabilities
- 60% of all working age Americans with disabilities NOT in the work force
- 7.5 million individuals have MR

- **14.3 million** persons, *age 21 to 64*, with disabilities employed:
  - 2.9 million with severe disabilities
  - 74.1% of 16.3 million with a disability, have private insurance have government plan coverage, and 18.7% have no coverage at all
  - 36.2% of the 13.2 million with severe disabilities have private, 48.1% have government plan, and 15.7% have no insurance

125 million newborn are born with MR each year